Biosocieties

SEARCHING FOR 'RELATIONS' USING A DNA LINKING REGISTER BY ADULTS CONCEIVED FOLLOWING SPERM DONATION

Dr Lucy Frith (corresponding author)

Dept of Health Services Research, University of Liverpool

Block B, The Waterhouse Blds, Brownlow Street

Liverpool, L69 3GL, UK

Tel: +44-151-795-5333

Fax: +44-151-794-5604

Email: frith@liverpool.ac.uk

Professor Eric Blyth

School of Human and Health Sciences, University of Huddersfield.

Dr Marilyn Crawshaw

Independent Researcher and Honorary Fellow, Dept of Social Policy & Social Work, University of York

Professor Olga van den Akker

Department of Psychology, Middlesex University, London, UK

ABSTRACT

This paper considers how sperm donor-conceived adults registered with a voluntary DNA linking register, UK DonorLink, constructed identity and relatedness by examining two areas: how their identity was affected by becoming aware that they were donor-conceived; and the process of searching for their donor and donor-conceived siblings. The views and experiences of donor-conceived adults has, until recently, been a neglected area. This study is the first to consider the experiences of those searching through a DNA-based register, and contributes to the growing literature on searching. This paper presents qualitative data from a questionnaire-based study with 65 adults conceived following sperm donation. It examines emerging linkages by investigating how ideas of relatedness, kinship and identity were enacted and how narrative certainties were moved and removed by opening up new conceptions of what it means to be 'related'. Their knowledge of being donor-conceived was both a powerful disrupter and a consolidator of family relationships. No single story of being donor-conceived emerged – with competing narratives about the effects and implications for respondents' kinship relationships and sense of identity. This study sheds light on how kinship relationships are negotiated and managed in adulthood by those conceived following sperm donation and how this can change over the life-course.

Key Words

UK DonorLink, kinship, relatedness, donor conception, sperm and gamete donation, identity

DONOR CONCEPTION AND ANONYMITY

The use of donor gametes in family formation has a long history but its use as a form of medical intervention is more recent (Richards, 2014). Donor insemination was first used in clinical practice in England in the late 1930s and was generally practised in secret (Nachtigall, 1993). Accepted practice, at least until the 1980s, was both to safeguard the donor's identity and to advise prospective parents to keep the donation secret both from their social circle and the child (RCOG, 1987). Gradual questioning of donor anonymity emerged in the 1980s. For example, in 1983, the Sperm Bank of California began recruiting donors who agreed to the release of their identity to offspring when they reached 18 (TSBC, 2015). Parallels were also drawn in the UK with adoption legislation in England and Wales that had allowed adopted people to access their birth records since 1976 and where 'best practice' increasingly emphasised the importance for adopted people to be able to trace their biographical roots (Triseliotis et al, 2005). When legislation was enacted in the UK, the Human Fertilisation and Embryology Act 1990 (hereafter "the Act") endorsed the principle of donor anonymity, but made provisions for unspecified non-identifying information about the donor to be released to donor-conceived people when they reached 18. The passage of the Act, however, did not put this issue to rest and donor anonymity continued to be questioned, culminating in the removal of anonymity in 2005 (Frith, 2015). As a result, donor-conceived adults are able prospectively to access identifying details about their donor (assuming they know that they are donor-conceived).

SEARCHING FOR 'RELATIONS'

Prior to the 1990 Act, there was no UK central register of information on fertility treatment cycles (those treated, the resultant children or donor information) and no statutory requirement on service providers to retain – or later release – any records that they had kept.

Thus, there is limited information available for donor-conceived adults born before the Act about anyone they are genetically related to as a result of donor conception. One way of tracing these 'relatives' is through DNA testing (Blyth, 2012). UK DonorLink (UKDL), founded in 2004 and funded by the UK government, was the world's first DNA based voluntary contact register.[1] Donors and donor-conceived adults registering with UKDL could submit a DNA sample to try and identify a *potential* link to another registrant. DNA testing only provides levels of probability of genetic relationships and tests are more reliable for donor-to-offspring links than those between donor-conceived siblings (see Crawshaw et al. 2013). This emerging science of DNA testing cannot provide absolute certainty but provides one option for searching for those without access to other information sources.

There has been relatively little research on the views and experiences of those who are donor-conceived (Hertz et al. 2013, for a review see Blyth et al 2012). This paper adds to this small but growing area of research and is part of a wider study on searching that included donors (see van den Akker et al 2015; Crawshaw et al, 2016). In van den Akker et al (2015) we reported that donor-conceived adults viewed their search positively, both those who had been linked and those who had not, and although some concerns about the searching process were mentioned, these did not prove to be a barrier to searching. Motivations for searching were varied with the most common being 'to satisfy my curiosity, 'to see whether we have anything in common', 'to access medical information' and 'to make me feel more complete in my identity' (see also later discussion in this paper). Having access to a DNA-based register was highly valued despite DNA results not providing absolute certainty although the only aspect where the majority anticipated possible difficulties was in 'getting false positive results'. Of those who had been linked, most reported direct, regular and continuing contact

[1] The functions of UK DonorLink were transferred to the Donor Conceived Register (http://donorconceivedregister.org.uk/) in 2013 and it ceased to operate.

which was mutually positive; some reported no ongoing contact and some reported negative consequences. Almost two thirds believed their sense of family and self had changed since being linked. We concluded that the donor-conceived adult respondents appeared to have thought carefully about searching and were undeterred by the uncertainties attached to DNA as a basis for linking. In Crawshaw et al (2016) we reported on respondents' views about the service provision itself. Support for access to psychosocial services was high and just over half would have welcomed direct access to a DNA specialist to explain the DNA results in more depth. We concluded that the drive to find genetic relatives appeared greater than any perceived downsides to the use of DNA, indicating that 'hope overrides caution' (Crawshaw et al 2016:17).

A number of other studies have been conducted with donor-conceived individuals searching for their donor-conceived siblings and donor (see Freeman *et al*., 2014), but none to our knowledge have examined the experiences of those searching through a DNA-based register. Studies have reported donor-conceived individuals' interest in donor-conceived siblings (Scheib *et al*., 2005; Mahlstedt *et al*., 2010; Rodino *et al*., 2011). Kirkman (2004a) recounted the experiences of a single participant who had located an undisclosed number of half-siblings. Jadva *et al*. (2010) surveyed 165 donor-conceived children and adults aged from 13 from the US-based Donor Sibling Register (DSR), a world-wide, non-profit organisation founded in 2000 with more than 52,400 registrants, the world's largest voluntary register. The DSR provides an online database where links can be made between people conceived by the same donor and, in some circumstances their donors. Links are made by donor number, clinic information and message boards. Forty two of Jadva *et al's* participants had located half-siblings and 40 had made contact. Blyth (2012) investigated eight adults conceived from a single donor who had discovered the identity of their donor and each other's existence and

their contact experiences. Finally, Cushing (2010), Jadva *et al*. (2010) and Beeson *et al.* (2011) considered the impact of searching for donors and/or donor-siblings on participants' relationships with their parents. Some negative experiences of donor-conceived individuals' contact – or attempted contact – with donors and donor-conceived siblings has been reported (Turner and Coyle, 2000; Beeson *et al.* 2011). For example, Cushing (2010) noted the frustrations experienced by some who had unsuccessfully tried to locate their donor-conceived siblings and donor. However, most studies have reported largely positive outcomes (Jadva *et al*., 2010; Beeson *et al.*, 2011; Blyth, 2012; Daniels *et al.*, 2012).

THEORETICAL FRAMING

Recently, there has been increased attention in sociology to theories of kinship as a useful lens through which to explore family relations, relatedness and connections (Mason, 2008; Kramer, 2011; Nordqvist, 2014). The study of reproductive technologies is productive for kinship studies 'because of its curious, paradoxical, domain-crossing nature.' (McKinnon, 2015:464) This study contributes to this body of literature. Carsten notes that many of the studies on reproductive technologies have concentrated on those undergoing treatment 'rather than what happens to kin relations outside these contexts or once treatment is over' (2004:174). Searches for donor-conceived siblings and donors are conducted outside the clinic and therefore away from the normative framework in which fertility treatment is conducted and enable donor-conceived individuals to create their own sense of family – one that changes over the life-course.

Donor conception both challenges and reinforces the importance of biogenetic relatedness. People want a 'child of their own' and this leads them to explore the option of using a donor. By using donor conception the child is not theirs in a strictly biological sense – (s)he may not

be genetically related to the future parents – but the child is theirs in the sense they have taken steps to instigate her/his existence, they 'intend' to parent (McKinnon, 2015). Thus, as Strathern (1992) notes, reproductive technologies create a new convention: a distinction between social and biological parenting that does not straightforwardly supersede the importance of biological links but instead displaces them to another domain. Hargreaves sees reproductive technologies as destabilising the analytical opposition between biological and social kinship (2006:262) and argues that the parents of donor-conceived children in her study worked hard to construct kin connections by blurring the boundaries between nature and culture. As Carsten says, the 'boundaries of what is constituted by biology or kinship are not set in stone, but may shift and merge in relation to one another' (2004:188).

Our analysis also draws on sociological conceptions of the family and relationships. There is a perception that the modern family is changing: how we define 'family' and what it means to be in a family, or have a family are areas subject to intensive discussion (see van den Akker 2006; May, 2011) and Smart (2007) has argued for a concept of 'personal life' that can encompass different forms of relationships. We will draw on Morgan's work (1996) that sees the family as something people 'do' – with families constituted by their customs and practices, rather than structural elements of relationships, marriage and household formation – to explore these 'new' families created by donor-conception. The family is seen as a fluid notion that can change over the life course, geographical locations and different spaces. Donor conception creates familiar and new family forms, unbounded and potential new kinship relations and introduces fluidity into family boundaries – both in terms of who is 'family' and how this changes over time.

Central to theories of kinship is how identity is constructed. As Lawler argues, 'identity itself is a social and collective process and not, as Western traditions would have it, a unique and individual possession.' (2014:2) One of these key collective processes is kinship: 'For its development of personhood a child needs to be fixed in relation with others and through its relatedness to them to society at large.' (Howell, 2003:466) Drawing on Erben, Lawler suggests that the contradiction between individualism and collectivism in Western culture is negotiated through kinship constructions (Lawler, 2014). Kinship plays a role in both how we construct ourselves as individuals and how we exist in commonality and is therefore of central importance for identity formation (Lawler, 2014. Carsten, 2004). As Bottero notes, identity is an 'over-extended concept' – all elements of life contribute to forming or influencing our identity. She breaks the concept of 'identity' into 'less congested terms', namely processes of 'self-understanding', 'identification and categorization' and 'commonality and connectedness' (2013:3). These can be used to unpick how the knowledge of being donor-conceived affected respondents' sense of identity, particularly with reference to 'connectedness'. Interestingly, the quantitative data from our wider study found that, collective identity (of belonging and family) was lower in donor-conceived respondents than the donor respondents (van den Akker et al., 2015). This prompted the question of whether the qualitative data could shed light on the underlying meaning, knowledge and awareness of being donor conceived, and these issues are addressed in this paper.

Drawing on Bottero's work, we will develop the concepts of epistemological and ontological work to distinguish between the effects that knowledge of donor conception had on meaning-making and identity. Epistemological work describes how this knowledge was used and understood, often as an explanatory tool, particularly in the context of relationships, to explain and understand the functioning of particular relationships (for example, why certain

relationships did not work). Ontological work is concerned with how becoming aware that they were donor-conceived affected respondents' identity, how they understood themselves in light of this information, and how they constructed new identities or questioned old ones.

THE STUDY

Methods

This paper reports on the qualitative data relating to identity, kinship and searching gathered from donor-conceived adults as part of a wider study of donor-conceived adults and gamete donors searching for genetic 'relatives' through a DNA-based registry. Although the UKDL was open to all donor-conceived people, partly due to the time period – pre-1991- that was covered by the register, all our respondents were conceived by donor sperm. The questionnaire survey used Bristol Online Survey software and included both quantitative structured questions and qualitative unstructured open ended responses. The quantitative data from both donors and donor-conceived adults have been reported previously (the authors, 2015). Respondents were provided with an information sheet and informed that their consent was implied by completion of the questionnaire. Ethical approval was obtained from Middlesex University and approval recognised by Universities of Liverpool and Huddersfield. The invitation to participate was sent out via UKDL Head Office to all those who were registered. The survey was open from mid-October 2012 to mid-January 2013.

All UKDL donor-conceived adult registrants (172) were approached, 65 (37.8%) of whom completed the questionnaires (four by hard copy). The mean age in years for respondents was 35.68, median age 43, range 21-65. The majority were female (50, 76.9%) and 14 (21.5%) were male – one respondent did not indicate their gender. This reflects the gender balance of UKDL registrants: 'There are currently considerably more female (127) than male

(47) DCA registrants.' (Crawshaw et al, 2013) One was Asian and the remainder Caucasian (full demographic and study information is reported in van den Akker et al, (2015). All respondents were conceived with the use of donor sperm, under conditions of anonymity and born before August 1991 (when the Act 1990 was implemented and a statutory central register of information established). All respondents had chosen to search for their biogenetic relatives *and* did so through the highly uncertain route of DNA linking and, therefore, constitute a particular group of donor conceived people. This paper gives an account of being donor-conceived in these specific circumstances and the results must be read in this context, recognising the specificities of this group. New technologies, such as DNA testing have created another route for searching when before people were almost wholly dependent on records to trace relatives. While this holds the potential for creating and recreating notions of relatedness and kinship, the inherent uncertainty of DNA testing also means that even 'scientific tests' cannot 'prove' who is one's kin. These technologies nevertheless shape anthropological and sociological understandings of what it means to be biogenetically related (Klotz, 2016). Kinship is always selective and our respondents' experiences of using the database enabled a particular form of kinship selection, and our data sheds light on how this is accomplished.

Data analysis

Some data reported here are responses to specific survey questions; others are themes that emerged from qualitative data gathered from free-text responses at the end of each section of the questionnaire. These allowed respondents to clarify and elaborate on replies as well as introduce areas 'outside' the specific questions asked. There are limitations to collecting qualitative data via surveys: it is not possible to probe responses or clarify understanding of the issues and questions; contextual data (voice tone, emotion and body language) are not

captured. However, surveys facilitate more data coverage and this study received a larger number of respondents and with a greater geographical spread than would have been possible with face-to-face interviews.

The quotes in this paper are followed by the respondent number and gender, i.e. R8F. While spelling has been corrected, language and grammar have been left in their original form. A thematic analysis was undertaken; transcripts were coded for concepts and the relationship between concepts explored using the constant comparative method (Silverman, 2006). The transcripts were read and coded using Atlas.ti software. The emergent themes and consequent analysis of the data were discussed between team members to reach agreement and explore different interpretations and linkages. Following Strathern, we will use the term 'biogenetic' to mean the genetic/biological relation, 'father' to mean the non-donor father and donor-conceived sibling to mean those conceived from the same donor, recognising that terminology in this area is never unproblematic and comes loaded with certain meanings (Freeman *et al*., 2014).

RESULTS

Most respondents discovered they were donor-conceived after the age of 11 (see table 1).

Ages at which donor conceived adults were told of their donor conception	
0-10 years	10 (15%)
11-20 years	24 (37%)
21-30 years	22 (34%)
31+ years	9 (14%)

Table 1

Of the twenty-three adults conceived following sperm donation with a link, six were linked to their donor and eighteen had been linked with between one and fourteen 'siblings'.[2]

Donor conception and identity

One of the key aims of the study was to locate the respondents' experiences of searching for 'relatives' within the context of their wider feelings and perspectives on being donor-conceived. Hence, respondents were asked if they were affected when they found out they were donor-conceived. The vast majority indicated that they were. Two respondents answered 'not applicable' - R14F, who had been told when she was three and R73F, who knew as early as she could remember. Although some other respondents had 'always known', that is known from a very early age, they nevertheless reported it having an effect. Proportionately more of those who became aware before the age of 11 reported no effect than in older age groups (see Table 2).[3]

Were you affected when you became aware of being donor-conceived?	**Yes**	**No**	**A little**	**Not applicable**
Age of finding out they were donor-conceived				
0-10 years N=10	3 (30%)	4 (40%)	1 (10%)	2 (20%)
11-20 years N=24	18 (75%)	0	6 (25%)	0
21-30 years N=22	17 (77%)	1 (5%)	4 (18%)	0
31+ years N=9	8 (89%)	0	1 (11%)	0
Total for all age groups N=65	46 (71%)	5 (8%)	12 (18%)	2 (3%)

Table 2

[2] This adds up to 24 as one respondent was linked to both siblings and donor.
[3] Although it must be noted that numbers in each age category of finding out are small.

One common theme was that awareness of being donor-conceived helped respondents make sense of their life, a form of 'epistemological work, that had an explanatory power. The knowledge that they were donor-conceived brought together elements of their biographies and sense of self that had previously been disjointed, enabling a more coherent narrative to be formed. These narratives were also were a form of ontological work, affecting how people constructed their identity. The following quotes illustrate how the discovery of being donor-conceived was both important for respondents' sense of self and how central this knowledge was to meaning-making – how they explained the biographical narrative of their lives.

It made sense of my life so far. I was aware that things had not always made sense before I was told. So decisions my parents had made became understandable. It hugely impacted my sense of my own identity and my feelings of self-worth. R17F (told when 21) [4]

Personally I feel that this explained huge parts of my life which seemed somehow wrong but I had no idea why. The sense of relief of finally having an answer to questions I hadn't vocalised was very welcome… a huge adjustment in my personal feeling of identity, overall positive. R12M (told when 36)

Initially shocked, but I knew my parents had problems conceiving so wasn't too great a leap. Now I find it really interesting and it fills in a few gaps (e.g differences to Dad's side of the family). R36F (told when 28)

One respondent, although reporting shock at finding out, also felt it made sense in terms of perceived differences between herself and her parents.

I was shocked and relieved in the first moment of finding out. The shock made me extremely emotional and I cried a lot. I also felt relief in knowing that I was not imagining things when I felt as though I were different from my parents. R39F (found out when 17)

To others, the knowledge they were donor-conceived came as a complete surprise and did not fit any previous sense of biography.

It rocked my foundation, it was completely unbelievable. Couldn't believe how naive I'd been for so long. Suddenly I have a void were I used to have a family history and relatives. I don't know who my dad is, who I am when I look in the mirror, where my son got his cleft chin from. R47F (found out when 40)

[4] To contextualise the quotes in this section we have added the age respondents were told or found out they were donor-conceived.

For some respondents this led to the feeling that there was a missing piece of their self that had profound effects on their sense of identity. This was conceptualised as a gap in their sense of kinship narratives and of what made them who they were – requiring ontological work to make sense of this new knowledge.

Have found it very hard to come to terms with. It's like a whole half of who I am and my history is just missing. R33F (told when 6)

I was shocked and surprised. The knowledge presented a whole new way of viewing myself in terms of identity, now having to incorporate the fact that one half of my genetic background was unknown to me. I was intensely curious about my donor father. R76F (told when 13)

This illustrates the connection between identity and kinship, an intense sense of identity loss could result, for some, from perceptions of a new kinship 'map' following disclosure. Yngvesson & Mahoney (2000) discuss how there is a 'subjectively experienced desire for rootedness, [and a] pull to identify oneself as exclusively one thing or another' (2000:78). This can have a profound effect, when an existing identity narrative is replaced with another, possibly competing, one. Here, another kinship identity is embodied in a donor father and an unspecified number of donor-conceived siblings and this 'new' basis for identity is unknown – they are no longer 'one thing or another'.

Some respondents reported how they had been able to fit this knowledge into their sense of self and biographical narratives. In doing so they were more likely to focus on ontological work alone, on the process of enabling them to feel more secure in their sense of identity. As Lawler notes in her study of mothers and daughters (who were biologically related), it is a choice which parts of kinship are embraced and constitute identity and which are not: 'This is active identity work in the context of kinship' (Lawler, 2014:52). For many of our

respondents, it was active ontological work, to make sense of themselves and assimilate this new information into their sense of identity.

It gave me a better sense of myself. I felt more grounded and it pleased me to know. R45M (told when 18)

I would say it took me about three years to come to terms with this news and sometimes I felt overwhelmed with grief and disconnectedness at knowing that I would never know who my donor was and I think this is what led me to join UKDL. I have now reached a stage in my life where I feel that 'I am what I am' and I do not have an overwhelming desire to know who my donor is, nor do I feel like 'half a person'. R39F (found out when 17)

Nevertheless, the challenge was to 'make sense' of this information, epistemological work, to try and fit it into some form of life narrative. The making of meaning in this way was a crucial part of respondents' response to this new knowledge.

It made me talk to my Dad about DC for the first time, it strengthened our relationship and helped me to become comfortable with being DC. R29F (told when 13)

Constructions of relatedness

How respondents saw relatedness and the origin of kinship bonds, biogenetic or social relationships or a combination, was a key theme in the data. This can be seen as part of how connectedness and kinship are constructed, as Nordqvist notes: 'Underlying engagements with kinship is a deep concern with being connected, and how to construct connectedness in everyday life. This leads me to suggest that we need to be sensitive to the multitude and shifting ways in which connectedness is known, and how it can be brought into existence and carry meaning in everyday life.' (2014: 269)

This study gives an insight into some of the 'multitude and shifting ways' connectedness carries meaning through the participants' epistemological work. By being aware they were donor-conceived, connectedness could be brought into existence (with donor relatives), reinforced with existing family or even removed from existence if there had been previous

poor relationships and feelings of not belonging. As only just over a third of respondents were linked (23, 35%), the majority of reflections on the effect of being donor-conceived on feelings of connectedness and constructions of kinship were about existing family (mother, father and the wider kinship networks on both sides) rather than 'new' relations. This provides an important perspective, as considerations of the effects of being told or finding out about being donor-conceived have often focussed on how the person sees their donor and donor-conceived siblings and the construction of these 'new' kinship relations. Data from this study contributes to the empirical research into how existing family relationships are affected (see Freeman *et al*., 2014), and how this knowledge can be seen as a powerful disrupter as well as consolidator of relationships.

Respondents were asked how the knowledge that they were donor conceived affected their relationships with their parents and their extended family (see Table 3).

Did this awareness affect your relationship with: (n=65)	**Parents**	**Extended family**
Yes	30 (46%)	10 (15%)
A little	16 (25%)	15 (23%)
No	18 (28%)	25 (38%)
Did not answer	1 (3%)	1 (3%)
Not applicable		14 (22%)

Table 3

Although the discovery of donor conception was a significant event that could not be taken lightly, responses to this question were nearly evenly split between those who felt they had been affected (46%) and 53% saying it had little or no effect on their relationships with parents or extended family. The following quote illustrates how relationships can be both reaffirmed and yet affected by the knowledge of being donor conceived and the act of searching.

The whole thing has been hard on my dad. He has been good to me but I am aware that he never really wanted to raise a donor-conceived child. He agreed because my mum wanted so

badly to have a baby. He is adopted and never tried to trace his biological parents. I think it has hurt him that I wanted to be on the donorlink register and was curious about my genetic background. He doesn't fully understand that its importance to me has nothing to do with my feelings towards him and doesn't mean I don't still think of him as my dad. R26F

For this respondent it is the act of parenting – the 'doing of family' in Morgan's (1996) sense – that is the most important element of creating kinship. Knowledge of the lack of biogenetic links has no impact on who she considers to be her dad. The bonds of kinship remained intact for some respondents after finding out they were donor-conceived. R77F explicitly points to the 'social connections' between her family which are foregrounded in terms of kinship ties.

The knowledge affected my relationship with my brother with whom I had been brought up in that we both shared this new knowledge. It did not mean that we were any less close, and we have remained close throughout our lives. My relationship with other aunts, cousins and so on has never changed, even though they know that we are not biologically related. We share the social connections of our family and that has held fast. R77F

Others felt that when the knowledge came late - in the case of R27F who had been told by her mother when at the age of 50 - there was no opportunity to reiterate connectedness.

I was totally stunned and very unhappy as I had had a fantastic relationship with my father and was proud to be his daughter. I think the worst part was the fact that, because he had died before I was told, I couldn't talk to him about it and tell him it was ok. R27F

Some respondents felt that this knowledge had had a profound impact on how they perceived their family relationships, especially with their father, and led some to no longer viewing him as a father at all. This was a form of epistemological work, it provided an explanatory framework for why their relationship with their father was unsatisfactory, even leading, in some cases to an 'unkinning' of their father.

Only with my "dad" who was in fact not my father. R24M

It explained a lot, as my father I believed to be mine wasn't and I built a stronger relationship with my mum. R41M

I do not speak to my father since I was 13 he wasn't around much when I was a child, so I don't feel any ties to him since we are not blood related. My mother and I have a very good and close relationship. R19F

In some ways, it made perfect sense. My father and I never had a bond really, he wasn't terribly interested in me, which affected me very badly as a child. I couldn't understand it. He was unfaithful to my mother continuously throughout their marriage and was almost quite blatant about this. This has affected my relationships as an adult. In some ways I got some closure from learning the truth because I could finally see that we didn't have a bond for a reason and not because of something I had done wrong. R42F

Father occasionally showed signs of discomfort or would hint at things implying he felt I was more 'foreign' to him. (He did not know that I knew). R25M

In these narratives, the lack of a biogenetic tie with the father is seen as disrupting the kinship relationship. One respondent felt that the poor relationship with her father was not her 'fault' but the 'fault' of the lack of blood ties. Here, biogenetic kinship is foregrounded (Strathern, 2005) and again used as an explanatory tool – for why the relationship with her father has not worked and the absence of a bond. The work that this form of biogenetic kinship is doing here is to construct an implicit assumption of a bond and, in the absence of this, to attribute it to the lack of biogenetic relationship. The lack of a biogenetic connection is thus seen as the causal explanation for the lack of a meaningful bond. This is epistemological rather than ontological, identity-work (though the latter may follow as a consequence), as the knowledge is used as an explanatory tool for why the relationship is not present or not working. As one respondent said,

I am angry that the man my mother was married to at the time (my 'Father') *used* the knowledge that he wasn't biologically connected to me, to walk away and leave when I was 10. (R9F - our emphasis).

This knowledge is *used,* brought into play, to explain why her father could leave her.

A similar form of disruption of kinship occurred, in some cases, with the respondents' extended family. Some portrayed this lack of connection as a feeling on their part.

None of my family had been told that I was donor conceived. It made me feel distanced from my father's family as I wasn't sure if they would still think of me in the same way if they knew that we weren't genetically related. It was reassurance from them that I needed, as I still wanted them to be my family. R29F

Although her father's family did not know she was donor-conceived, she felt that this lack of 'genetic' connection could be problematic and that they might cease to see her as 'kin' if they knew.

For R56F, it was her relationship with her mother's family that was 'disrupted', regardless of her biogenetic relationship to them.

Did not affect relationship with close family members (mother, brother, aunt, cousins, grandmother), but some extended family (great aunt and their family) told my mother that they did not consider me 'biologically part of the family' because of the way I was born. This was despite being born from my mother's egg and donor sperm so just as much a part of the family biologically as any other member! However I wouldn't say that it had a negative effect on me (it upset my mother more than myself). R56F

Here, donor conception does not problematize the biogenetic relationship, rather, it creates aspects of identity formation that are not seen as 'fitting' in with previous kinship narratives of how the child was brought into being, i.e. a baby created by two people in a loving relationship through sexual intercourse (Yngvesson & Mahoney, 2000). This point is further illustrated by the following respondents.

The "Paternal" side of the family now no longer accept me as part of their family since learning of my being donor conceived 3yrs ago based on their religious beliefs. R9F
The extended family on my mother's side have very little to do with us now. R30F

As Kramer has noted, certain kin can be rejected if 'the connectedness might be problematic.' (2011:391). As donor conception (and indeed many matters surrounding sexuality and reproduction) are often perceived as shameful family secrets (Smart, 2011), the mechanism of reproduction can also lead to 'de-kinning' (Edwards, 2014). Edwards uses this term, drawing on the work of Howell, to show how the kinning process is not always about creating kin but also removing kin. Howell examines how adopted people are kinned by their adoptive parents which requires kinship to be 'de-biologizing' (Howell, 2003) and hence requires them to be

‘de-kinned’ from their biological parents. This process can be seen in donor conception, where some of our respondents experienced a form of ‘de-kinning’ where previous kin relationships are disrupted; this was not always due to a lack of a biological relationship, but sometimes due to the families’ views of donor conception itself.

Often relationships with the mother were most affected. This was not due to what might be seen as biogenetic dissonance (since all respondents were biologically related to their mother) but instead to difficulties with the culture of secrecy around their conception (see authors forthcoming).

I still call my dad "dad" but as we don't have that much of a close relationship anyway, it didn't affect our relationship. I think the real change was with my mum who initially flat-out refused to talk to me about anything to do with it. When I went to a UKDL meeting, she got very upset and angry and said that it was nothing to do with me and that it had happened to her, so didn't understand why I needed to go. Things are a little better now but it's not something she feels entirely comfortable talking about, which is difficult for me.R28F

At first I was devastated, but then began to realise why I had a difficult relationship with my mother. R61F

Although these maternal relationships are reported as being problematic, there is no talk of kinship disruption (as there was with the fathers). Their mother is still their mother; it is just a complicated relationship and such complications often characterise family bonds of any stripe.

Searching

The two previous sections have illustrated the impact of the knowledge of being donor conceived on respondents’ sense of identity and their kinship relationships and these come together in the process of searching for donor-conceived relatives. The reasons for searching were bound up with the themes discussed: to give them a greater sense of themselves and to

create new relationships and families (see also van den Akker et al, 2015). These reasons for searching mirror those expressed by adopted adults searching for their birth parents: either 'identity completion' or seeking 'new relationships' (Crawshaw, 2002).

It is a fundamental quest to find family and get to know them and feel a part of a new family and be accepted by them. This is not a minor or trivial thing. R17F

To find medical history and try and fill the void left by losing half of my heritage. R47F

Finding something out about my heritage would change my life forever... I knew that if there was some information about me, that even if I didn't follow it up, I would always know about that relative being out there somewhere, I couldn't 'un-know' it. Was in two minds about whether it would be a benefit or a burden. R42F

Parallels may also be drawn here with work on those who are researching their family history. Kramer argues that genealogical research has three functions in personal life. It maps connectedness through blood (although not straightforwardly); it is used as a resource for identity-work and allows belonging in time and connectedness historically but also, 'belonging in new, or newly reconfigured places of significance.' (Kramer, 2011:392). Bottero (2013) also highlights the identity formation aspect of genealogical searching and this can be seen as a form of 'ontological work'. '(re)establishing connections with ancestors as people, and of the transformation of prior understandings of belonging and connection).' (2013:14); All these elements were present in our data and often with an increased emotional intensity as, rather than trying to find information about long dead ancestors or dispersed extended family, our respondents were searching for more immediate family.

Some respondents saw the connection with donor relatives as essential to completing not only a part of themselves but also their own children.

I am very glad I started the search as I now understand myself a lot better and I feel my four daughters have also gained a great deal from finding members of their biological grandfather's family. R27F

Most of the links made were with donor-siblings, with only six linked with their donors. Such linkages often resulted in new connections and kinship relationships being developed.

I have found the search and discovery of the identity of my donor father as well as half-siblings has been extremely significant for me. I consider myself incredibly fortunate to have enriched my life by getting to know these important "new" family members in my middle age and have happily embraced them in my life circle.R77F

The search was exciting, the unveiling of new sibs exhilarating. I am so grateful UKDL exists. I love my adopted sister but we both know we would never be more than casual acquaintances if we met through work for example. My donor sibs may not look like me, but they feel like me - we seem to think and laugh alike and it is wonderful to feel that sense of belonging.R55F

Here 'ontological work' is displayed (Finch, 2007). The sense of belonging and increased self-understanding all show how these kinship relationships create a new sense of identity for some respondents. Notions of kinship change over the life-course – giving a temporality to kinship – that is often not sufficiently recognised. Discourses of resemblance and similarity pervade this idea of biogenetic relations, as Schneider notes: 'aspects like temperament, build, physiognomy and habits are noted as signs of this shared biological makeup, this special identity of relatives together' (1968:25). Several respondents remarked on the existence of such similarities.

The similarities in personalities and interests we have noticed are uncanny! R17F
I have been amazed by how many similarities there are.R65M

Howell (2003), as noted earlier, talks of this 'kinning-work' in relation to adoption where self-conscious kinship (by parents) is engaged in to create permanent kinship bonds. Our data reveals an almost opposite process. The differences between donor conception and adoption are brought out as, although the parties are biogenetically related, other aspects of kinship relations such as social ties, even of a minimal nature, are absent and respondents have to do kinning-work to create these aspects of kinship bonds. Respondents engaged in kinning-work with varying degrees of success.

It can be a very emotional experience, being linked with half siblings. There is not always a connection, though when there is it's wonderful.R1F

One issue was the large numbers of donor-conceived siblings that sometimes emerged and the associated difficulty of forming close relationships across such a large group.

One of my last sisters, who turned up nearly three years ago, has become a good friend and we talk regularly on the phone and I have two other sisters who I also met through UKDL who I have frequent and very friendly contact with. There are an awful lot of us and I am in close contact with five of them and sporadic with two others, with occasional contact with most of the others. Some don't want contact with any of us. R1F

However difficulties were not exclusively related to numbers. One respondent had experienced particular problems with her donor-conceived sibling.

My relationship with my half-brother started out very positively, but became very intense very quickly (we were talking on the phone for hours, texting and e-mailing each other most days etc.) and then things started to go wrong…. At the time this seemed fine but with hindsight I don't think it was wise. The relationship then became very problematic, with issues of jealousy, possessiveness and neediness… I don't know what will happen in the future but at the current time I don't see myself staying in contact with him….I may have had problems with my half-brother, but he is my kin and I'm glad I met him. He does look like me physically and it was great to meet somebody who looks like me and is like me in temperament in many ways. I have learned things about myself through meeting him. Meeting him hasn't put me off looking for other relatives, I would just be more careful next time.R20F

Here there is recognition that despite these similarities (he looks like me, is similar in temperament) the kinship bond may not be enacted through the development or maintenance of any meaningful social relationship. Here biogenetic kinship becomes more fluid and more a 'family of choice' (Weston, 1991). Without the social, practical and physical bonds that often come attached to biogenetic kinship, this type of kinship can become contingent and negotiated (Mason, 2008). A close social bond is not presupposed by a biogenetic link and how these relationships are negotiated in practice depends on the individuals involved.

DISCUSSION

This paper examined the experiences of donor-conceived adults who were registered with UKDL, focussing on the impact that being donor-conceived (and finding out) had on their sense of identity, their family relationships and their experiences of searching for donor relations. There are limitations to our sample. As well as using only survey-gathered data, it cannot be seen as representative of all donor-conceived people: all respondents were already aware of their donor-conception origins, prepared to search for 'relatives' and had chosen to do this through a DNA-based register with the attached uncertainties of this route. Further, respondents were largely women, reflecting the larger number of women registered with UKDL and gendered participation rates in research involving donor-conceived people more generally (Culley, et al., 2013).

This is not the first study on donor-conceived adults searching for relatives, but the first to examine those searching through a DNA-based register. There are similarities in findings from other studies, notably with those using the Donor Sibling Registry. Therefore, this study adds to the volume of research in this area. The corroboration of previous findings is valuable, as it builds up more in-depth and nuanced knowledge of the area and begins to build a fuller picture of the wider psycho-social implications of forming a family through gamete donation. Finding links was generally experienced as positive; searching could be emotionally challenging; and relationships with existing families could be affected. The use of a DNA linking service presents unique challenges; respondents were prepared to use the service even when potential linkages would only carry a level of probability that there was genetic relatedness and not certainty. It is of note that these uncertainties with the knowledge produced by DNA testing did not come through strongly in the qualitative data. Indeed when considering those who had been 'linked' there was nothing to suggest that uncertainty of

genetic relatedness played a role; rather there appeared to be an assumption that this was 'certain' knowledge.

The age of becoming aware of their donor conception appeared to affect its impact on respondents – the younger the age of finding out the less 'disruptive' the effects appeared to be, as has been found in other studies (see Hertz et al, 2013). However, even some of those told during childhood could still find it profoundly hard to come to terms with this knowledge, challenging the over-simplistic idea that knowing about donor conception at a relatively young age enders it unproblematic. Such difficulties may have reflected the extent to which parents were comfortable about their use of donor conception. Berger and Paul (2008) found that even in some families where there had been disclosure, the use of donor conception remained a difficult issue, one that was never talked about and where the children were told not to tell others. This can be seen as an example of the distinction that Gillis (1996) makes between actual families (the family we live with) and the idealised family of our imagination (the family we live by). Not actively acknowledging donor conception can be used to construct this 'idealised' family and to paper over aspects that do not fit within it, such as conceiving children via donor conception rather than 'naturally'. Hence, there appears to be a need to 'do' family in a certain way and perform biological kinship. As will be noted later, some families may need support to manage this form of family construction.

In terms of relationships with their fathers, respondents often used the new knowledge of being donor-conceived to rationalise pre-existing poor relationships. It is beyond the scope of this study to determine why these relationships were poor and the part played in that by donor conception (including disclosure) rather than other factors. However, some respondents

believed that these poor relationships resulted from their father not being their biological or 'real' father.

We developed the concepts of epistemological and ontological work to distinguish between the effects that knowledge of donor conception had on meaning-making and on identity. Epistemological work explained how such knowledge was used as an explanatory tool, for why certain relationships did not work for example. Ontological work followed on from becoming aware they were donor-conceived and how this affected self-identity, what was needed to be done to form a new or different identity. These two types of 'work' were related but distinct; the knowledge that one was donor-conceived did not always significantly impact on identity. There was no single story of being donor conceived nor of the effects this had on identity and/or kinship relationships – the meanings were not uniform. There were competing ways of creating narratives and this knowledge could both create and fill a void in senses of identity.

A key theme in debates over kinship in reproductive technologies is the place of the biogenetic relationship and how it is 'choreographed' (Thompson, 2005), that is how something is reassembled to bring into existence new kinds of relationships (for example how our respondents 'created' new kin by the process of searching). Levine argues that kinship models created by non-traditional families use both conventional and radical ideas to reference biogenetic connections. Searching for donor relatives represents for Levine, 'the persisting cultural emphasis on biogenetic connection in Euro-American and other societies, as providing a basis for common identity, as conferring irrevocable kinship.' (Levine, 2008:385). Our data did not suggest this to be straightforwardly the case. Although the existence of biogenetic relationships was the basis for kinning-work in some cases and the

lack of such ties could be problematic, particularly in constructions of fatherhood, in others non-biogenetic relationships were still privileged and the existence of biogenetic ties did not automatically form the basis for socially enacted kinship.

There is a body of literature on the work that parents do to create kinship bonds with donor-conceived and adopted children (Hargreaves, 2006; Nordqvist, 2014; Howell, 2003). Such work 'claims' the child as part of the intending parents' kinship network and constructs the meanings of family relationships with both the parents and 'others' (the gamete donor or birth parents). Although 'self-conscious and temporal practices of kinning' are efforts to 'fix them [the adopted child] permanently not only into the present, but also into the past of their new family and kin' (Howell 2003:468), there is a further temporal dimension to be considered – the future. Our study shows how this work might be 'un-done' or reconstructed when donor-conceived people become active agents in their own lives – the boundaries of kinship set by the parents may either hold or be re-made when the child becomes an adult. The adult 'child' has greater control over how kinship is 'done' and can construct their own sense of 'family'. Thus, kinship work is ongoing and never 'settled' – different parties will make and un-make bonds. This temporality of kinship relationships is often overlooked, they are not set at birth or childhood, but evolve and the meaning of being donor-conceived can also change over the life-course.

There are a number of policy implications of this research. First, it is clear that more support is needed for parents in handling how to tell their child and manage the ongoing discussions and dialogue that this should entail. As noted just because telling is done at a relatively young age, this in itself does not ameliorate any possible effects. Disclosure is a process rather than an event and ongoing support is needed for parents and donor conceived families as the

children are being brought up (see Fine, 2017). Helping children to make sense of donor conception and families to incorporate it into their family narratives is a form of epistemological work. This will, in some cases, benefit from professional and/or peer guidance and support. Second, donor-conceived adults could benefit from some kind of support and preparation when beginning to inquire about and possibly search for their relatives through donor-conception (see Crawshaw et al, 2016). As has been noted (Scheib et al, 2017) with increasing numbers of parents disclosing to their donor-conceived offspring and the increasing availability of DNA testing (Harper et al, 2016), donor anonymity could well become a thing of the past, and the issue of appropriate support and information for those using and born from donor conception becomes more pressing. There are also further areas for research suggested by our data that could be explored: how people searching through DNA databases conceptualise and manage the uncertainty of the results; how becoming parents themselves might affect donor-conceived people's views of kinship; how the resonance of information and searching passes down the generations; whether the absence of donor information contributes to discomfort or dissatisfaction about being donor-conceived even among those who were told of their origins in childhood; and how these kinship (or other) relationships created by searching, i.e. finding donor conceived relatives, develop or change over the life-course, and how embedded these new relationships become. Although a number of these areas are not new research questions, there is a need for more longer term follow up and understanding of how donor conception is experienced over the life-course and how kinning and unkinnng have important temporal aspects that have hitherto not been fully explored.

CONCLUSION

In sum, when thinking about linkages between, donor-conceived individuals, donors and donor-conceived siblings, identity is, in some cases, still embedded in a form of biogenetic connection. However, this connection is not one straightforwardly associated with kinship as it has been formulated in the Euro-American tradition. Here, as Kramer (2011) notes, the role biogenetic kinship plays is 'selective' and it can be invoked as important or discarded. The 'relations' and concepts of relatedness formed by donor-conceived individuals between their donor and/or donor-conceived siblings raise unfamiliar constructs and these coexist with, and reinterpret, familiar kinships forms – creating 'new' and fluid family forms.

Acknowledgements

We would like to thank the staff of the UKDL and all those who responded to our survey.

REFERENCES

van den Akker, O. B. A. (2006) A review of Gamete donor Family Constructs: Current research and future directions. *Human Reproduction Update* 12(2): 91-101.

van den Akker, O. Crawshaw, M. Blyth, E. Frith, L (2015) Expectations and experiences of gamete donors and donor-conceived adults searching for genetic relatives using DNA, linking through a voluntary register, *Human Reproduction* 30 (1) 111-121.

Beeson, D., Jennings, P., Kramer, W. (2011) Offspring searching for their sperm donors: How family type shapes the process, *Hum Reprod* 26:2415–2424.

Berger R, Paul M. (2008) Family secrets and family functioning: the case of donor assistance. Family Process. 47(4):553-66.

Blyth, E. (2012) Discovering the 'facts of life' following anonymous donor insemination, *I J Law, Policy and Family* 26:143–161.

Bottero, W. (2013) Identity and the practice of family history. CRESC Working Paper Series, No 121.

Carsten, J. (2004) *After Kinship*. Cambridge: Cambridge University Press.

Crawshaw, M., Gunter, C., Tidy, C., Atherton F. (2013) Working with previously anonymous gamete donors and donor conceived adults: UK DonorLink, *Hum Fertil* 16: 26-30.

Crawshaw, M., Frith, L., van den Akker, O. and Blyth, E.D. (2016) Voluntary DNA-based information exchange and contact services following donor conception: an analysis of service users' needs *New Genetics and Society* http://dx.doi.org/10.1080/14636778.2016.1253462

Crawshaw, M. (2002) Lessons from a recent adoption study to identify some of the service needs of, and issues for, donor offspring wanting to know about their donors' *Human Fertility* (5) 6-12

Culley, L. Hudson, N. Lohan, M. (2013) Where are all the men? The marginalization of men in social scientific research on infertility. *Reproductive BioMedicine Online,* 27, 3:225-235.

Cushing A. (2010) 'I just want more information about who I am': The search experience of sperm-donor offspring, searching for information about their donors and genetic heritage, *Inf Res* 15(2).

Daniels, K. R., Kramer, W., Perez-y-Perez, M. V. (2012) Semen donors who are open to contact with their offspring: issues and implications for them and for their families, *Reprod Biomed Online* 25: 670-677.

Edwards, J. (2014) Undoing kinship. In Freeman, et al. (eds) *Relatedness in Assisted Reproduction.* Cambridge University Press.

Finch, J. (2007) Displaying families. *Sociology* 41(1): 65–81.

Fine, K (ed.) (2015) *Donor Conception for Life,* Karnac Books.

Freeman, T. et al. (2014) Making connections: contact between sperm donor relations. In Freeman, et al. (eds) *Relatedness in Assisted Reproduction.* Cambridge University Press.

Frith, L. (2015) The Limits of Evidence: Evidence based policy and the removal of gamete donor anonymity in the UK. *Monash Bioethics Review.* I33 (1) 29-44.

Frith, L., Jacoby, A., Gabbay, M. (2011) Ethical Boundary Work in the Infertility Clinic, *Sociology, Health and Illness* 33 (4): 570-585.

Gillis J (1996) A World of Their Own Making. Boston, MA: Harvard University Press.

Hargreaves, K. (2006) Constructing families and kinship through donor insemination *Sociology of Health & Illness* 28(3): 261–283.

Harper, J.Kennett, D, Reisel, D. (2016) The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business. *Human Reproduction.* doi:10.1093/humrep/dew065

Hertz, R., Nelson, M. Kramer, W. (2013) Donor conceived offspring conceive of the donor: The relevance of age, awareness, and family form. *Social Science & Medicine* 86: 52-65

Howell, S. (2003) Kinning: The creation of life trajectories in transnational adoptive families. *Journal of the Royal Anthropological Institute* 9: 465–84.

Jadva, V., Freeman, T., Kramer, W., Golombok, S. (2010) Experiences of donor offspring searching for and contacting their donor siblings and donor. *Reprod BioMed Online* 20:523-532.

Klotz, M. (2016) Wayward Relations: Novel Searches of the Donor-Conceived for Genetic Kinship, *Medical Anthropology*, 35:1, 45-57,

Kirkman, M. (2004) Genetic connection and relationships in narratives of donor assisted conception, *Aust J Emerging Technol Soc* 2:1-20.

Kramer, A-M. (2011) Kinship, affinity and connectedness: Exploring the role of genealogy in personal lives. *Sociology* 45(3): 379–95.

Lawler, S. (2014) *Identity: Sociological Perspectives.* Polity.

Levine, N. (2008) Alternative kinship, marriage and reproduction, *Annual Review of Anthropology* 37; 375-389.

Mahlstedt, P., LaBounty, K., Kennedy, T. (2010) The views of adult offspring of sperm donation. *Fertil Steril* 93:2236-2246.

Mason, J. (2008) Tangible affinities and the real life fascination of kinship. *Sociology* 42(1): 29–45.

May, V. (2011) (ed) *Sociology of Personal Life.* Palgrave Macmillan.

McKinnon, S. (2015) Productive paradoxes of the assisted reproductive technologies in the context of the new kinship studies. *Journal of Family Issues* 36(4): 461-479.
Morgan, D (1996) *Family Connections*. Cambridge: Polity Press.

Nordqvist, P. (2014) Bringing kinship into being: connectedness, donor conception and lesbian parenthood, *Sociology* 48(2): 268-283.

Richards, M. (2014) A British history of collaborative reproduction and the rise of genetic connection. In Freeman, et al. (eds) *Relatedness in Assisted Reproduction.* Cambridge University Press.

Rodino, I., Burton, P.J., Sanders, K. A. (2011) Donor information considered important to donors, recipients and offspring: an Australian perspective. *Reprod Biomed Online* 22:303-311.

Royal College of Obstetricians and Gynaecologists (1987) *Donor Insemination*. London: RCOG.

Scheinder, D. (1968) *American Kinship: a cultural account.* University of Chicago Press.

Scheib, J. Ruby, A. Benward, J. (2017) Who requests their sperm donor's identity? The first ten years of information releases to adults with open-identity donors, *Fertility and Sterility*, http://dx.doi.org/10.1016/j.fertnstert.2016.10.023

Scheib, J., Riordan, M., Rubin, R. (2005) Adolescents with open identity sperm donors: reports from 12-17 year olds. *Hum Reprod* 20:239-252.
Seale, C. (1999) *The Quality of Qualitative Research* SAGE, London.

Silverman, D. (2006) *Interpreting Qualitative Data: Methods for analysing talk, text, and interaction*, Third edn, SAGE, London.

Smart, C. (2011) Family secrets and memories. *Sociology* 45(4): 539-553.

Smart, C. (2007) *Personal Life: New Directions in Sociological Thinking*. Cambridge: Polity Press.

The Sperm Bank of California (2015) About section of website https://www.thespermbankofca.org/content/identity-release-program (accessed 21st April 2015)

Strathern, M. (1992) *Reproducing the future: Anthropology, kinship, and the assisted reproductive technologies*. London: Routledge.

Strathern, M. (2005) *Kinship, Law and the Unexpected. Relatives Are Always a Surprise*. Cambridge: Cambridge University Press.

Thompson, C. (2005) *Making Parents. The Ontological Choreography of Reproductive Technologies*. Cambridge, Massachusetts: MIT.

Triseliotis, J., Feast, J. & Kyle, F. *(*2005*) The Adoption Triangle Revisited: A Study of Adoption, Search and Reunion Experiences. BAAF*, London.

Weston, K. (1991) *Families We Choose: Lesbians, Gays, Kinship*. Colombia University Press, New York.

Yngvesson, B & Mahony, M. (2000) 'As one should, wants and ought to be': Belonging and authenticity in identity narratives. *Theory, Culture and Society* 17(6): 77-110.